

# COUNTY VOICES

## Invisible Struggle— Living With Hope

— By Kristin Means

Everyday you pass people like me on the street. We smile, look normal, but you have no idea what is going on beneath the surface. The way I look is no reflection of how healthy I am. Underneath my skin, I am actually falling apart as I struggle daily with simple tasks. For ten years, I suffered from chronic, nearly debilitating pain, and despite aggressively seeking answers from many doctors, I was never able to find answers for my suffering. Last year, I finally received the answer for which I had been looking. It came in the form of a life-changing diagnosis of Ehlers-Danlos Syndrome (EDS). The diagnosis was bittersweet. I finally had answers to why my body seemed to be falling apart, but my life would never again be the same.

EDS is a genetic disorder that causes a defect in connective tissue, the tissue that provides support to many body parts such as the skin, muscles, blood vessels, ligaments, and other organs. The fragile, stretchy skin and unstable, hypermobile joints found in EDS happen because of faulty collagen. Collagen is a protein, which acts as a “glue” in the body, adding strength to connective tissue. The collagen in your body essentially holds it together.

Without proper treatment and monitoring, EDS can be life-threatening. Even with treatment EDS is debilitating. There is no cure for EDS. The longer EDS is left untreated in a symptomatic person, the worse it gets. That is why early diagnosis and education is extremely important. EDS is known as the invisible illness because we look just like everyone else and seem to have normal, healthy lives. We’ve had to live with our physical difficulties our whole lives, so many of us have learned how to smile through a great deal of pain. Unfortunately, due to misunderstandings about EDS and despite my symptoms, it took me twenty-nine years to receive my diagnosis.

Growing up, I was always flexible, prone to injury, and constantly had aches and pains. I frequently needed surgeries to correct my injuries. I was very active in sports and mistakenly blamed my injuries on overusing my body. When I was nineteen my pain had become nearly unbearable and I was no longer cleared to play collegiate softball. My symptoms baffled doctors, due to the lack of awareness about EDS. As a result, I received many misdiagnoses. When I was finally diagnosed, last year, I felt as if my identity had been stolen. My life, as I knew it, would be different, forever. I realized that I would not be able to continue doing many things that I enjoy. Since there is no cure for EDS, I have had to completely adapt my lifestyle.

One adaptation is bracing. As my joints become more and more unstable, I need to brace them to hold them in place. I have braces for my hands, neck, back and ankles. There is not a minute, of any day, that I forget I have EDS. I must make choices daily on how I will exert my energy and body. I must maintain awareness of every movement. Something as easy as putting on a shoe can dislocate the joints in my hand. As a mom, I find great joy in the simple embrace of my children. However, if I choose to hold one of my kids for a few minutes, I struggle with serious pain the remainder of the day and into the next day. Tasks, thought to be simple by most, can become huge challenges for me.

People who have EDS often struggle with other disorders as well. Without receiving the proper care, my body had been unnecessarily damaged. As a fourth grade teacher, I love my job, but was left with no choice but to take the year off to have a series of surgeries. In



Kristin and Michael Means with their sons, Braeden and Brody.

April, 2010 I had a brain surgery that corrected four different problems. The surgery was for a chiari malformation, it realigned and fused my cervical vertebrae to my cranium, and fixed the angle of my brainstem. My other surgeries have included a tethered spinal cord, two surgeries for hydrocephalus, and a thoracic outlet syndrome surgery that involved removal of a rib. With a family at home, and not being able to take care of myself at times, the struggles I have faced in the last year have been extremely challenging, emotionally and physically. Thankfully, I have amazing people surrounding me who have supported me and helped me to stay positive.

I have known for years that I was ill. What I was not prepared for was the reality that my genetic illness would not stop with me. I had a fifty percent chance of passing EDS to each of my two boys. We were devastated when my oldest son, Braeden, tested positive. He will face immense challenges in his life and will not be able to play the sports he loves. Our hopes and dreams of what the future held for the family had fallen apart in a matter of months. Thinking of

Braeden going through the struggles that I have faced hurts worse than any pain with which I have had to deal. As difficult as this is for our family to accept, we actually feel blessed because we are one of the lucky EDS families. With early diagnosis we can be proactive with treatments. At four years old, he has faced adult problems and has amazed us with his ability to adapt with a smile. Throughout his life, he will be closely monitored by doctors. In addition, he will require genetic counseling and therapy. All of these adaptations will help him to have the best quality of life possible.

Early diagnosis of EDS is crucial in order to manage symptoms. The lack of awareness about EDS leads to many children being misdiagnosed with growing pains. Early diagnosis can prevent serious damage to their young bodies. As a parent, you want to help your children to have long, happy lives. Unfortunately, most parents who unknowingly have children with EDS may never see their children experience the quality of life they may have otherwise enjoyed with an early diagnosis. This is why awareness about EDS is extremely important. EDS awareness impacts the lives of not just one person, but entire families.

Family and friends often resort to putting their lives on hold to help us get through ours. Although this isn't the life I would have dreamt for my family, my diagnosis has changed my purpose in life. My purpose, now, is to do as much as I can to raise awareness of EDS, early diagnosis, treatment, and support groups. Many do not have the support to help them make it through each day. Throughout the difficult journey my family has faced, we feel blessed with those around us. We have had the opportunity to see how caring people can be. Each person, who has helped my family through this difficult time, has made a difference in our lives, and made me feel very fortunate to have such a great support system. We know that although we will have our struggles, we are in a caring community who will support us through anything. We are grateful. —CSM

*To learn more about EDS, please visit [www.ednf.org](http://www.ednf.org). To offer much-needed support to help fight EDS, please visit their web site: [www.firstgiving.com/fundraiser/kristin-means/kristinmeans](http://www.firstgiving.com/fundraiser/kristin-means/kristinmeans)*

*To view Kristin's film about life with EDS, visit the Cecil Soil web site at [www.cecilsoil.com](http://www.cecilsoil.com)*

*Thank you!*



Kristin and Braeden



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